Patient autonomy must be interpreted in a social context and does not exempt health workers from their responsibility. Legislation which is based on patient autonomy provides no guarantee that the patient’s best interests will be safeguarded.

**No man is an island**

An article in this issue of the Journal of the Norwegian Medical Association tells the story of a woman suffering from a serious, degenerative disease, who decided to reject further treatment and died as a consequence (1). A number of health workers were involved. To some of them, the case presented a moral problem and they submitted it to the Clinical Ethics Committee.

The article addresses a number of problems, some of which are related to publication ethics: For example, should consent have been obtained prior to publication? If yes, then from whom, given that the patient herself is dead? The authors base their exposition of the case on conversations with only a limited number of the health workers involved — could the article thereby be perceived as biased? What about the concern for those who have not been heard while at the same time being exposed to some degree of criticism? Should a major public interest outweigh such objections? The manuscript has been thoroughly discussed by the editors. We maintain that publication can be defended on the grounds that two basic criteria are fulfilled: the narrative has been de-personalised to the greatest possible extent and the next of kin have been informed and have provided consent.

The issues associated with the story itself are nevertheless more important, since they challenge a fundamental principle of medical ethics: the principle of patient autonomy or right to self-determination. Three questions are especially pivotal: What is the specific content of the principle of autonomy? Can the principle of autonomy exempt health workers from their responsibility? Is legislation based on the principle of autonomy able to safeguard the patients’ interests?

Justifications of the principle of autonomy are frequently based on liberalist philosophy: Humans, it is claimed, are rational «masters of their own house», and should therefore be free to decide on matter related to their own life situation. This fundamental view has come under attack from several quarters — some critics refer to this notion of humans as «the neo-liberal fiction», claiming that it undermines the preconditions for provision of care (2). Instead, the principle of autonomy should be perceived in a social context. From birth, people are interwoven into a multiplicity of relationships, and our relations to others will thus be decisive for and an integrated part of our own identity (3, 4). Autonomy will therefore not imply that we can do whatever we want with no concern for the social consequences of our actions (5, 6). Another objection is related to the criteria that must be fulfilled for an act to be considered truly autonomous: is it sufficient that the patient has (perhaps fleeting) desires or emotions, or does autonomy pre-suppose a rationally based determination that concurs with the personal- ity and the social community of which this person is a part? (7) Finally, one may ask whether the things that benefit one’s own life are exclusively a matter of subjective assessment — even though only I can feel my own pain, other people may also be knowledge- able about what could help me feel better (8).

In other words, the principle of autonomy is more problematic than what is often seen in print. However, even when the principle is interpreted in light of liberalist philosophy, there is often a major gap between theory and reality. A Norwegian review article presented three preconditions that must be met for a decision to be characterised as autonomous: the patient must possess a sufficient understanding of all alternative actions, he or she must be able to provide consent (which includes the ability to apply relevant information to his or her own life situation) and the decision must be voluntary (9). How often are these preconditions fully met in clinical practice? The story told by Hofset Larsen and collaborators in any case leaves some room for doubt (1).

On the other hand, this may equally well be a story about renouncement of responsibility. Because, when the principle of autonomy is interpreted in a social context, the obligations of health workers cannot be restricted to providing information and subsequently leaving the patient alone with the decision. Such a patient would most likely feel betrayed, rather than autonomous (2, 5). Our job is the opposite, to strengthen the patient’s ability to articulate personal desires and needs, and this requires care, trust and an emotional engagement. Moreover, we should challenge the patient’s arguments and viewpoints, and even attempts at persuasion may occasionally be warranted, without this being a violation of the principle of autonomy (8, 9). Finally, according to Norwegian law, the doctor responsible is obligated to assess whether the patient is in fact able to provide consent (9). All this requires wisdom, experience and tact — in brief: «the art of healing».

The art of healing cannot be provided by way of legislation, contrary to what liberalist philosophy so often presumes. The story told by Hofset Larsen and collaborators testifies to the inadequacy of the law and thus becomes an example of the criticism raised against the liberalist understanding of the principle of autonomy and the appurtenant advance of law into the field of ethics (2). There are indications that this patient’s best interests were not adequately safeguarded, despite our comprehensive rights-based legislation. To rephrase: patients are, like it or not, at the mercy of our personal characteristics — our virtues, if you like (6). The problem can be formulated in an even more salient manner: Can we build a good society in the long term if morality — our social glue — is no longer regulated by way of virtues, but through legislation? (3, 10) Does the story of the woman who died illustrate the dark side of modern society, in which community has been replaced by individualistic loneliness? It seems appropriate to bear in mind the warning given by the Renaissance poet John Donne — «No man is an island». 

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References